

# Like Mother, Like Son

By Robin Yamakawa



Valerie and Charles Stahl use their experience to try and help others.

Parents and their children naturally have a lot in common. While some kids have their parents' eyes or sense of humor, Charles Stahl, 7, and his mom Valerie of Grosse Pointe, Mich., share an extra bond. Both have juvenile rheumatoid arthritis (JRA).

"I was a year old and so was he," says Valerie explaining when they were both diagnosed.

Understanding what it is like to have the same disease, they are always there for each other – Valerie giving him weekly shots when he needed them and Charles giving his mom support.

And now, the two have hit the road to raise arthritis awareness to help others. They have done a couple of speeches for the local chapter of the Arthritis Foundation in their native Michigan and the pair traveled together in February to the Arthritis Advocacy summit at in Washington, D.C.

Once there, they went to Capitol Hill to encourage lawmakers to pass the Arthritis Prevention, Control and Cure Act. The proposed law would give more money to arthritis research and focus attention on kids with arthritis. On Capitol Hill, Valerie and Charles were able to meet with staff members of seven Congress members from Michigan and let their representatives know about what life with arthritis has been like for them.

## Same Disease, Different Treatments

Although they both have the same disease, Valerie and Charles' experiences with it have been very different, particularly in the way the disease is treated now compared to when Valerie was Charles' age. She says money that has gone to arthritis research has made the difference in dramatically advancing arthritis treatments, which is why she is doing what she can to advocate for the Arthritis Act.

Valerie says that her treatments were almost "barbaric" in comparison to treatments Charles now receives. For Valerie, every summer she was checked into the hospital for special treatments. She spent time in full leg casts and wore braces on her wrists and heels.

"They thought keeping the joints immobile was the answer," explains Valerie. "It wasn't until I was 19 that I got on good medicines."

At 18, Valerie had her bottom jaw rebuilt. It had stopped growing at age 7 and doctors replaced her jaw with two of her ribs to prevent jaw problems later on. She has had multiple replacement surgeries and revisions, 13 in all.

Charles has been more fortunate. He was first diagnosed after Valerie noticed swelling in his left knee. Valerie says she knew what she was looking at because of her experience and pushed for a quick diagnoses and treatment. But it was rough at first.

"He stopped walking, he would not crawl," Valerie recalls. "He used his forearms to pull himself like a snake. He would cry when we put on shoes. He wouldn't let me hold his hand."

Charles was receiving two weekly shots of methotrexate until recently but has now improved enough just to receive the nonsteroidal anti-inflammatory, *Naprosyn*.

And Charles stays active. "I like to play chess and bowl and I like to play with my friends," he says.

## New Found Friends and Meaning

At the Children's Advocacy Summit in Washington, D.C. he got to meet, play and learn with more than 30 other kids with arthritis and some of their siblings. That is something he normally doesn't get the chance to do. Like most kids with arthritis, Charles knows very few kids with his same disease.

"I am the only one at my school," says Charles. "I feel like I am the only one in the whole world."

But by attending the summit and other Arthritis Foundation activities, Valerie and Charles have met a lot of people with arthritis and it's made the tight-knit pair even closer.

"I was looking forward to the plane ride and meeting other kids with arthritis," Charles told *KGAT* at the summit. "So far, I like everyone but what I like the most is

spending time with my mom."

Valerie also enjoyed the extra quality time and, over the course of the trip, even found a greater meaning behind it all.

"To try and get the bill passed, it made having the arthritis worth it," she says. "You always wonder why, what the purpose was? It was that we were meant to try and get the bill passed and get a little more involved and see all the progress." ★

## Scenes from the Summit

A lot of exciting things happened at this year's Arthritis Foundation Advocacy Summit, including the highest attendance ever. The Children's Summit taught kids about our government and how they can get lawmakers to help people with arthritis.

### In case you missed it, here are some highlights:

- Thirty-three kids and 10 teens representing 18 states attended this year's Arthritis Foundation Advocacy Summit.
- Kids listed not liking getting shots, the bad taste of their medicine and not being able to keep up with their friends as the top reasons for not liking arthritis.
- At the end of the summit, these newly trained advocates went to Capitol Hill with their parents to share their stories and convince their Congress members to pass the Arthritis Prevention, Control and Cure Act.
- Special fake money was made to remind Congress members how little is spent on juvenile arthritis research each year – just \$23 per kid with arthritis. Advocates passed out the fake money on Capitol Hill.